## An Open Letter To: Researchers with Expertise in Infection-Associated Chronic Illness

Re: Program Manager Opportunities at the Advanced Research Projects Agency for Health (ARPA-H)

ARPA-H (the Advanced Research Projects Agency for Health) recently initiated the process for hiring the first cohort of program managers (PMs). More information about the hiring process is below.

This letter is being shared to encourage people with expertise in infection-associated chronic illness to consider pursuing this opportunity.

ARPA-H was established by Congress in March 2022. Its mission is to invest in break-through technologies and broadly applicable platforms, capabilities, resources, and solutions. These investments will aim to transform important areas of medicine and health for the benefit of all people and will seek outcomes that cannot readily be accomplished through traditional research or commercial activity. Its programs will enable ambitious efforts to solve hard problems that are keeping people from better health - focusing on high-risk, high-reward research projects to find, create, and accelerate high-impact health solutions. More information is available at: <a href="https://arpa-h.gov/">https://arpa-h.gov/</a>

This first cohort of PMs will enjoy an unprecedented opportunity to transform entire fields of research and open new avenues for discovery and innovation. Like DARPA, the agency APRA-H is modeled upon, individual PMs will have broad autonomy to identify promising opportunities and direct significant investments in those areas. As was noted in a 2020 paper on the need for ARPA-H, "DARPA PMs have the resources and authority to invest in multiple approaches to a given goal. DARPA proposals are openly competed, but PMs can strategically select the winners in a way that creates a diversified, risk-mitigating project portfolio."

This letter is being sent by a coalition of organizations that work on behalf of patients, families, and caregivers who have had their lives upended by complex, multi-system, infection-associated chronic illnesses. Such illnesses include Long COVID, myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), dysautonomia (including postural orthostatic tachycardia syndrome [POTS]), mast cell activation syndrome (MCAS), and chronic Lyme disease/post-treatment Lyme disease syndrome (PTLDS), to name a few.

These medical conditions have long been under-resourced and under-acknowledged. The understanding of their underlying mechanisms has consequently languished, as have efforts to

<sup>&</sup>lt;sup>1</sup>Michael Stebbins and Geoffrey Ling, *Creating the Health Advanced Research Projects Agency (HARPA)*, Day One Project, April 19, 2020,

https://www.dayoneproject.org/ideas/creating-the-health-advanced-research-projects-agency-harpa/

improve their diagnosis, treatment, and prevention, all of which requires innovative, integrative, and interdisciplinary approaches.

The impetus for this letter is the recognition of the immense potential for ARPA-H to address these long-neglected conditions and alleviate their burden on society. ARPA-H presents a unique and profound opportunity to advance the science of and facilitate effective treatments for infection-associated chronic illnesses, and, at long last, to improve function and quality of life in the many millions living with these disabling conditions.

We need people like you to be involved in launching and shaping this new organization, by championing and contributing to an ARPA-H program focused on infection-associated chronic illness.

Information about the hiring process at ARPA-H is now available at: <a href="https://arpa-h.gov/careers/program-managers/">https://arpa-h.gov/careers/program-managers/</a>

A key part of the application process will be providing responses to the "ARPA-(H)eilmeier Questions," which are based on the set of questions developed by former DARPA Director George Heilmeier. These questions are included below as an attachment.

We appreciate your interest in these issues and your commitment to this work. If you have any questions about this letter or the information it presents, please contact <u>ben@meaction.net</u>.

With hope, sincerity, and appreciation,















## **ARPA-H Program Manager Application Information**

From: https://arpa-h.gov/careers/program-managers/

## **Transform the Future of Health**

If you have a bold, ambitious idea and feel you would be a good fit for ARPA-H, please complete the form below and submit your cover letter, CV, and idea or concept that addresses the ARPA-(H)eilmeier Questions.

ARPA-H will support concepts brought to life directly from Program Managers that have not only identified a key problem in health today, but are also passionate about a vision to bring forward revolutionary solutions to solve the problem, and do so in an equitable way. ARPA-H embraces a culture of open innovation and empowers its program managers to fearlessly pursue health breakthroughs that cannot readily be accomplished through traditional research or commercial activity.

Program managers at ARPA-H will serve a term-limited appointment of three years, and no more than six years total, to ensure a constant rotation of new ideas and diverse perspectives.

## **ARPA-(H)eilmeier Questions**

\*Answers required as part of initial concept submission

Based on a set of questions developed by former DARPA Director, George H. Heilmeier (1975-1977), known as the "Heilmeier Catechism," the ARPA-(H)eilmeier Questions provide potential ARPA-H PMs high-level guidance for what information should be included in their proposals, as well as allow PMs to communicate to ARPA-H leadership what they hope to accomplish with the program.

Vision statement: "Imagine if..." -> one sentence that describes your concept as a potential new health future.

- 1. What are you trying to do? What health problem are you trying to solve? Articulate your objectives using absolutely no jargon.
- 2. How is it done today? What are the limitations of present approaches?
- 3. What is new about your approach? Why do you think you can be successful at this time?
- 4. Who cares? If you succeed, what difference will it make?
- 5. What are the risks? Identify any risks that may prevent you from reaching your objectives, as well as any risks the program itself may present.
- 6. How long will it take?
- 7. How much will it cost?
- 8. What are your mid-term and final exams to check for success?
- 9. To ensure equitable access for all people, how will cost, accessibility, and user experience be addressed?
- 10. How might this program be misperceived or misused (and how can we prevent that from happening)?